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ABSTRACT

Although studies of social contact and mutual aid between the elderly and their children suggest impressive potentials for family supports, much less is known of this potential in a situation of illness and dependency. The family's potential at that stage when the older person's health deteriorates to the point that some external support is required was examined. Subjects were 170 families drawn from hospital discharge records and interviewed two weeks later. Findings indicate that, while the motivation of children to provide support was unusually high, situational impediments were likely to intervene, and center on job responsibilities, care of other dependents, and higher priorities on the marriage and family of orientation. The major family caretaker was likely to be a spouse or sibling, often in poor health himself. Despite the numerous difficulties experienced by those in poor health who were being cared for by others in the same status, a high valuation on their own independence prevented the search for other alternatives. (Author)

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# Impediments to Family Supports to Dependent Elderly: An Analysis of the Primary Caregivers*

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Studies of social contact and mutual aid between the elderly and their children suggest impressive potentials for family supports. Most elderly have children and most are in daily or weekly contact with at least one of them. Even siblings are a source of sociability among at least one-third of the elderly. Thus, survey data over the past two decades have documented the high level of contact, a level which has remained basically unchanged (Shanus, 1973; 1978). This type of survey research, however, can only measure contact, so we have less understanding of the quality of contact or the degree to which contact in itself can meet the needs of the impaired elderly (Johnson, 1978).

Less is also known in this country on these potentials for support in the event of illness and dependency. We do know that most impaired elderly are cared for by a family member upon discharge from hospitals (S. Brody, 1978; Eggert et al. 1977). Furthermore, there is no evidence that children reject a parent outright when support is requ red. When an elderly parent becomes ill, offspring usually rise to the occasion to provide needed assistance. Most research, however, points out numerous realistic impediments

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to family supports when the type of support required must extend beyond social contact and intermittent aid, to provide comprehensive daily care. In such situation, there is evidence that it imposes strain on the caretaker (Isaacs, et al, 1972; Karcher and Linden, 1974; Sanford, 1975; Sainsbury and Grad de Alarcon, 1970; Savitsky and Sharkey, 1973).

From a demographic perspective, the most serious impediment is a scarcity of family members available. As young adults, large numbers of the elderly delayed marriage or remained permanently unmarried so that today there are fewer children on whom they can call (J. Treas, 1977; E. Brody, 1978). Changes in our family system have also weakened the potentials for family supports as more and more women work and as families move from one place to another. Thus, we can conclude that while most elderly have at least one offspring available, few perhaps have an extensive family network on whom they can rely, at least in contrast to the extended family system in other time periods when there were higher rates of fertility, traditional sex role arrangements and residential stability (Lopata, 1978).

The real test of family resources center upon the capacities available at the point when declining health creates problems of dependency which require assistance from others. Before family supports as alternatives to community or institutional supports become a major cornerstone in health policy, several issues need further clarification and key questions need to be answered through systematic research.

First, does the high level of social contact found between the elderly and their children signify adequate social support? Does this contact stem from duty-bound obligation or is it a genuine source of both sociability and real assistance?

Second, how does an adequate support system fare in the event of illness and dependency which requires more comprehensive care? In other words, will a daughter or son who intermittently chauffers a parent to a doctor's appointment be able to provide more comprehensive care when a parent becomes more seriously disabled.

Third, what are the dynamics of the support process? Need we distinguish between tangible support such as direct services from the affiliative supports directed at emotional and sociability needs? How well do these supports bear up over a long time period?

Fourth, who are the family supporters? What are their ages and their relationship to the patient? How close do they live? How many individuals are involved? What is their health status?

## Background of the Study

This paper is a preliminary report of research which is directed toward these questions. It is a study of 170 families of elderly individuals who had some health impairment. The sample was drawn from discharge planning services of two hospitals in San Francisco and was confined to White Catholics and Protestants of European ancestry. Although the elderly had an acute condition requiring hospitalization, almost all of them had at least one chronic condition which caused some limitation upon their activities after discharge. All of the patients had at least one relative in the Bay Area. Focussed interviews were conducted with the elderly individual and in most cases their major caretakers several weeks after discharge and again 6-9 months later.

In most cases, the individuals over 65 had numerous hospitalizations for

one or more of their chronic conditions. However, their level of impairment varied greatly from those who could perform most of the Activities of Daily Living (OARS) without help to those who were bedridden and needed round-the-clock care. The disposition after discharge on the whole reflects their functional capacities.

Upon discharge from the hospital, the following arrangements were chosen:

- 17% went to nursing homes or other long-term care situations.
- 55% returned to their former living situations with a family member to assist them.
- 13% returned home with both family and community supports.
- 6% returned home with the help of community supports.
- 8% returned home with no supports.

From these percentages, we see that over half of the patients with a family member available could return to their former living situation with the support of a relative. When those who used both family and community support are added, over two-thirds of the elderly have this resource.

The 17% who entered long-term care institutions were invariably quite impaired and required extensive care. Usually family supports had preceeded institutionalization. Those who returned home with no reported supports on the whole were relatively healthy. Certainly these figures suggest that family supports can be mustered in the event of illness if the individual has at least one family member in the community.

However, when we turn to the primary caregiver, his or her age, and relationship to the patient, a note of caution must be introduced:

| Relationship of Primary Caregiver | Percent |
|---|---|
| Spouse | 37 |
| Offspring | 30 |
| Siblings | 6 |
| Other relatives, (niece, nephew, grandchild) | 7 |
| No one* | 20 |

*Respondents insisted they cared for themselves and needed little help from others.

When these findings are combined according to age sets, we can see that the impaired elderly are more likely to be cared for by an age peer, a spouse or a sibling (43%) than they are by a younger and presumably healthier offspring or other relative (37%). When those elderly who insist on caring for themselves are added to those with a caregiver who is in old age, we can conclude that the primary caregivers for almost two-thirds of the sample (63%) are the elderly themselves.

On the whole the situation was mutually agreeable to the elderly and their offspring. Very few of those over 65 complained of filial neglect. In fact, they were adamant about their independence and sought to explore every means to maintain it. Almost two-thirds of those over 65 were identified as highly independent. They neither wanted nor expected a son or daughter to change their activities to provide support as long as they could maintain their present situation or had a spouse available to assist them. They also expressed concern over the possibility they would become a burden to their children or others. This fear of dependency was prominent and in some cases

prevented the patients from seeking the help that they needed.

A content analysis of the children's motivation reveal that this situation was not a result of low motivation or their rejection of their parent. Where children are available, about 75% were well motivated if the need arose. In many cases, however, these offspring had numerous competing commitments which would require some change if they took over the major support of their parent. Demands from a job or from a spouse or children were the most frequently mentioned impediments to caregiving among the younger age groups. While numerous children resided in the Bay Area (within one hour's drive), even this distance sometimes prevented all but the most perfunctory care. In some cases, a recent divorce of a daughter or son added additional impediments to their playing a supportive role.

Another factor emerging from this research is evidence that usually only one individual was the primary caregiver rather than a pool of available relatives. When the spouse was present, that individual was primary caregiver. When there was no surviving spouse, the responsibilities fell upon a son or daughter. If an offspring was not available, a sibling might step in. If none of these resources existed, other relatives usually provided some assistance. For example, a niece or nephew was identified as the major individual who assumed responsibility. However, by the time one had to rely on a relationship of that kinship distance, the caregiving differed vastly from the more comprehensive type provided by a spouse or an offspring. With more distant relatives, help was more perfunctory with little emotional content. This relative mostly functioned as an intermediary between the elderly patient and the health care bureaucracy and their major responsibility involved arranging for hired help. Some of these respondents identified

their motivation for assuming this role with an aunt or uncle as stemming from some unpaid debt to a deceased parent rather than genuine affection or loyalty to the aunt or uncle.

The impediments to family supports also differed greatly depending upon the age of the caregiver. For the spouses and siblings, the major impediment was their own health. Over one quarter of the caregivers over 65 reported health problems. In fact, it was difficult in some cases to identify who was the patient and who was the caregiver, for the family member on the admission forms was often more impaired than the patient. (At the 6 month followup, some of these caregivers had died or had become more impaired themselves.)

The B's are an appropriate example of this rather common situation. Two years ago they had moved to the West Coast to be near their only child, a daughter in her late fifties. Mrs. B had had a leg amputated from diabetes, so they wanted to be near their only close relative. Mr. B suffered a stroke soon after their arrival and lost his driving license. Both have great difficulty in performing any activities requirng mobility, such as shopping and going to the doctor. Their daughter expressed great concern over their situation but could only come for two hours a day. She worked and had a family of her own which required her attention. The B's limited income provided coverage for only a few additional hours each day and nursing home care was beyond their means. Their assets were too high for Medicaid coverage and their income was too low to support both of them in institutional care, a solution both of them saw as the only viable alternative.

Less dramatic but still serious problems were found in other situations where the patient was being cared for by an age peer. The situation was

vulnerable because of the increasing likelihood that the caretaker would also become ill. However, as long as a spouse was still alive, no alternatives were usually sought.

The sons and daughters who bore primary responsibility for the patient reported different types of difficulties. Forty percent described the situation as stressful to them in terms of their mental health. The second highest number of complaints centered on the effects it had had upon their social life. The activities involved in assuming the helping role acted to reduce their other social contacts. Apparently these efforts acted to isolate the caregiver from social support rather than stimulate the formation of an extensive supportive primary network. Twice as many described this as an impediment as those who reported impediments from the competing priorities from a job or spouse and children. In other words, the supporters of the elderly apparently needed a social support system themselves, but the demands of the caregiving more often increased their social isolation.

Mrs. G. provides a good illustration of this situation. She is in her mid-forties and has four children of her own. Since she is the only daughter or daughter-in-law who does not work, her father's long physical decline and eventual institutionalization placed her in the strategic role of caregiver. Since her mother developed behavioral problems in the process, her duties did not end with her father's nursing home placement. She comes into the City from a suburb 30 minutes away each afternoon to visit her father, shop and run errands for her mother and provide some companionship for both of them. While her husband and children have been quite supportive to her, they provide little concrete assistance. Her siblings only provide minimal

help, and the series of events over the past year have not increased the contact and sociability between them. Her major complaint was the change in her life which removed her from her usual activities with friends and her married children.

Preliminary analysis of our data suggest that the optimal situation, that of a pool of individuals cooperating in the caregiving, does not usually occur. Instead the responsibilities fall upon one individual, usually the spouse. In the case of widowhood, the offspring becomes the primary individual, but usually only one offspring assumes the role of major caregiver. In many cases only one offspring is available either due to the small size of the family of orientation or the geographic mobility of siblings. In other cases, there is no long-established family patterns of reciprocity which can be activated, so it is rare to find a sibling group cooperating and interchanging caregiving. Since responsibility usually fell upon one individual, that individual often becomes overtaxed. It is not surprising that stress is reported frequently among offspring or that assuming the role tends to isolate rather than integrate them into a wider social network.

## Conclusion

These findings, however preliminary, point to important dimensions of the American family system which must be examined when one is evaluating the potentials for family supports. The first has to do with the nature of primary social network in the average family and the degree to which it can be mobilized in the likely event of illness among its elderly members. There are usually few individual members who are in frequent contact and engage in reciprocal aid. With no close-knit and connected kinship network,

the resources of the family are abbreviated even if the motivation is high.

In addition to the problem of resources and the absence of longterm patterns of reciprocity, dominant values on family affect what one actually does when the need arises. Nuclear families are expected to be independent from the kinship group and its priorities come before those of the kinship system. An optional rather than an obligatory set of norms provide directives, so that independence rather than interdependence usually results. While there are variations on the acceptance of these directives based upon ethnicity (Johnson, 1979), one can only assume that the magnitude of the support actually delivered by relatives is determined by the number of competing priorities an individual faces. His or her own family of procreation should, and usually does, come first. Furthermore, the elderly themselves as products of our culture generally espouse the same values and consciously avoid making demands.

Ethel Shanas (1979) identifies the process of family supports as "the principle of substitution." Where the primary relative is not available, another is quite willing to assume the supportive role, the inference being that one individual is usually enough. However, a case by case analysis suggests that if one exhausts all intimate kinship resources to the point one must reach out to distant relations for help, the type of care differs greatly and rarely centers on day-to-day care of physical needs as well as social and emotional needs. Neither friends nor relatives of second or third degree can substitute for a spouse or an offspring in the extensiveness of the care nor its quality. Most importantly, where extensive care is needed, more than one individual is required to provide optimal care without undue strain.

Ideally, the principle of substitution is quite functional in view of the decreased numbers of relatives an elderly individual today has available. However, I would propose any kinship principle should also have an additive component. In other words, the optimal family support situation should be the joint cooperation of several relatives, so that the burdens of care do not overly tax one individual.

Most kinship networks, however, are not usually cohesive enough or contain enough individuals in proximity who are linked into a closeknit reciprocal exchange system. As we saw in this research, increasing social isolation rather than social integration results when a son or daughter takes over the responsibility. The low level of density, in network terminology, imposes some costs on the caregiver.

The second consideration on the assets of the family stems from an analysis of the age of the caregiver. The impediments facing an offspring are realistic hurdles. The competing priorities from a job or the demands of their nuclear families are such that in many cases a major reorganization of their lives is required. On the contrary, a spouse or sibling caregiver is vulnerable to illness and dependency, so that single reliance on age peers runs the risk of being a temporary and vulnerable arrangement.

All evidence point to the conclusion that marriage is the key relationship in the event of illness in old age. In fact, the reliance upon a husband or wife and his or her willingness to provide assistance is unquestioned. It is never a matter for options; rather it is a "given" accepted without reservation. This is a complementary relationship where the interdependence and reciprocity built into it are prominent. The idea expressed

by most is "I care for my spouse now, for the situation could easily become reversed and I would need the same type of care."

In contrast to this complementary relationship in a marriage, the parent-child relationship is colored by a diametrically different system of norms. The symmetry and exchange so characteristic of the marital relationship are notably absent. Since most elderly parents who are chronically ill have few resources to bestow in return, the costs of care giving - emotional, financial and so on - usually outstrip the rewards. The relationship, however, is ascribed, and few offspring reject their filial duties. Since the obligation itself is implicit and specific norms as to what one must actually do are notably absent in our society, there is considerable leeway in meeting these expectations and few sanctions imposed for notable neglect. At the same time, a son or daughter in middle age probably has more competing priorities pressing upon them than at any other stage in their lives. It is not surprising that so many find these responsibilities to be stressful.

It is clear from this research and from other evidence that the problems of family supports do not stem from a problem of motivation. No close relative willingly rejects or abandons an elderly family member. Even when there are serious impediments facing the caregiver, such as poor health or numerous competing relationships, every effort is made to assume the helping role. Rather the problem is one of resources in terms of personnel. There are often few individuals available, so that duties can be interchangeable. Thus the one individual who takes over the care can become overtaxed and also in need of support. It is this situation which should be heeded when the question of family supports is considered in policy decisions.

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